

# Quality of life in cancer patients – an hypothesis

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## Author's abstract

*Quality of life is a difficult concept to define and to measure. An hypothesis is proposed which suggests that the quality of life measures the difference, or the gap, at a particular period of time between the hopes and expectations of the individual and that individual's present experiences. Quality of life can only be described by the individual, and must take into account many aspects of life. The approach is goal-orientated, and one of task analysis. The hypothesis is developed in a diagrammatic way, and several methods of testing the hypothesis suggested.*

'The longer I live, the more I am satisfied of two things. First that the truest lives are those that are cut rose-diamond fashion with many facets. Second, that society is always trying in some way or other to grind us down to a single flat surface'.

*The Professor at the Breakfast Table.* Oliver Wendell Holmes.

In recent years, improvements in cancer treatment have emphasised the importance not only of the short-term, but the long-term implications of therapy. The term 'quality of life' (or more correctly 'good quality of life') is being increasingly used. Because of the cultural and psychological overtones associated with cancer, it is a useful model to use in the study of this topic, though it should not be considered that 'quality of life' is only relevant to the cancer patient. Far from it, the concept is an important one in all forms of illness, as indeed it is in health. The term 'quality of life' extends not only to the impact of treatment and side-effects, but to the recognition of the patient as an individual, and as a whole person, body, mind and spirit. A study of the quality of life is difficult for two reasons. Firstly, there is a real problem in defining what is meant by 'quality of life'. Secondly, even if this were possible, there remains the difficulty of quantifying 'quality of life' and of comparing one individual with another. There is also the related, but equally important fact,

## Key words

Quality of life; cancer; task analysis; nursing process; problem-orientated medical records.

that measurement may not be important from the point of view of the patient. Action may be required to modify the existing quality of life. Thus measurement and action need to be linked.

## Measurement of quality of life

Increasing attention is being paid to the measurement of quality of life in cancer patients. This has ranged from the use of linear analogue scales to assess well-being, mood, level of activity, symptoms, social activities, and anxiety (1), to questionnaires which measure life events (2). Many of the currently used methods are based on life areas or have adopted a task analysis, or problem-orientated approach (3,4,5). Others have emphasised the importance of the subjective aspects of quality of life, and the importance of the patients' perception of their health (6,7). The psychosocial aspects of health have also been studied separately (8). De Bono in his book *The Happiness Purpose* has used the concept of 'life space' and its development in relation to happiness and quality of life (9). Many attempts have therefore been made to define the quality of life.

The definition used below seeks to put quality of life into perspective from the patient's point of view, as it is the patient's perception which is important. The definition is not claimed to be original, rather it brings together several related concepts. More importantly it may allow the quality of life to be measured and an assessment made of the effectiveness of any action initiated to modify it. The definition given is essentially the statement of an hypothesis which requires to be tested, and which uses the cancer patient as a model for the study of this concept. The aim of this paper is to stimulate discussion on the theoretical basis of measuring and defining quality of life.

## A definition of 'quality of life'

The quality of life can only be described and measured in individual terms, and depends on present lifestyle, past experience, hopes for the future, dreams and ambitions. Quality of life must include all areas of life and experience and take into account the impact of illness and treatment. A good quality of life can be said to be present when the hopes of an individual are

matched and fulfilled by experience. The opposite is also true: a poor quality of life occurs when the hopes do not meet with the experience. Quality of life changes with time and under normal circumstances can vary considerably. The priorities and goals of an individual must be realistic and would therefore be expected to change with time and be modified by age and experience. To improve the quality of life therefore, it is necessary to try to narrow the gap between hopes and aspirations, and what actually happens. The aim therefore is to try to help people to reach the goals they have set for themselves. A 'good' quality of life is therefore usually expressed in terms of satisfaction, contentment, happiness and fulfilment and the ability to cope. This definition emphasises the importance of personal growth.

From this definition of quality of life certain implications follow:

- i) It can only be assessed and described by the individual.
- ii) It must take into account many aspects of life.
- iii) It must be related to individual aims and goals.
- iv) Improvement is related to the ability to identify and achieve these goals.
- v) Illness and treatment may well modify the goals.
- vi) The goals must be realistic.
- vii) Action is required to narrow the potential gap. This may be by the patient alone or with the help of others.
- viii) The gap between the expectation and the reality may be the driving force for some individuals.
- ix) As each goal is achieved new ones are identified, opening the gap again. It is a constantly changing picture.

Quality of life therefore, measures the difference, at a particular moment in time, between the hopes and expectations of the individual and that individual's present experiences.

#### THE DIMENSIONS OF QUALITY OF LIFE

Basic work by Flanagan (4) and others has stimulated the concept of 'life areas'. Such areas cover all aspects of life and can provide a useful checklist which will enable the patient or the caring team to identify those aspects which are of particular importance to the individual. The patient's own problems and priorities can then be identified. Such life areas include: home and garden, work, hobbies, financial problems and body image, diet, mobility, ambitions, spiritual problems, concept of the future etc. The identification of problems and priorities makes it possible to develop realistic goals and to use these to assess progress and measure the reduction of the 'gap'. This allows the hypothesis to be tested by evaluating the effectiveness of the specific intervention.

#### The representation of quality of life

To develop this concept further a series of diagrams will be used to illustrate the hypothesis.

- 1) The hopes, ambitions and dreams of the individual

are shown in the upper line (Figure 1) varying naturally with time. In reality, the here and now, there is also variation, and the gap between hopes and reality may never be bridged. There are periods of good times and bad times. The gap therefore measures the quality of life. For many individuals it is the need to close the gap which provides the driving force of personal ambition and achievement. The activity necessary for narrowing the gap may be associated with as much satisfaction as the end result.

- 2) The impact of illness may vary depending on the time at which it occurs (Figure 2). When things are going well the individual may be able to cope with illness, when they are not, it may be the last straw.

- 3) Illness may modify the quality of life in several ways (Figure 3). For some patients the quality of life may be enhanced, and the so-called 'benefits of illness' may occur. For others the quality of life may be greatly diminished. In some patients following illness, life may be characterised by wide swings in quality with highs and lows, while for others it becomes flat and dull.

- 4) To improve the quality of life it may be necessary either to reduce some of the expectations and ambitions, or to increase the quality of life as it is (Figure 4). To decrease the expectations does *not* mean denying hope, rather it makes the expectations more realistic. The patient is encouraged to develop appropriate goals. In terminally ill patients for example it may be unrealistic in some patients to continue to pretend that things will improve. For others the denial of this may be critical in maintaining the quality of life. Hence the importance of individual interpretation of the size of the gap.

- 5) The 'here and now' profile is a composite of many aspects of life and not all need to increase to improve quality and narrow the gap (Figure 5). Illness or ageing, for example, can inhibit further development of a physical nature. Yet the individual can continue to grow and develop in other ways, socially, psychologically, emotionally and intellectually. It follows therefore that to improve quality of life in those who are ill requires a minimisation of physical problems and an enhancement of other aspects of life.

- 6) Some individuals are able, therefore, to have a good quality of life even though they may appear to have major problems, for example serious physical illness or poor social conditions. They are able to achieve this either by reducing their expectations and being satisfied with what they have, or by being able to rise above the problems by personal growth and development. It is *not* possible to make value judgements about other people's 'quality of life'. It is their own perception which matters. Conversely for some patients, 'trivial' events may have a major impact on life and may be much more important than 'cancer'.

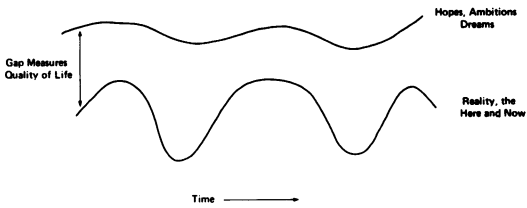


Figure 1) A representation of the gap between reality and hopes, dreams and ambitions.

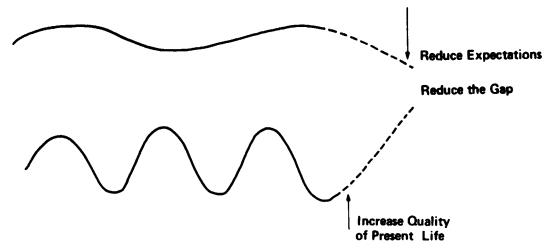


Figure 4) The improvement in the quality of life represents either a reduction in expectations or a change in the present mixture of reality.

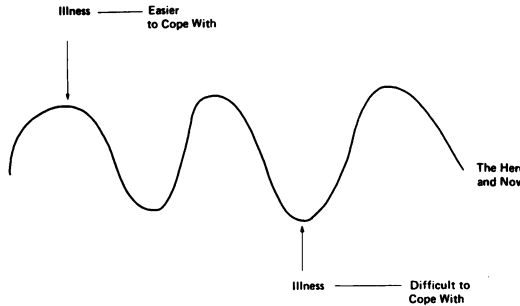


Figure 2) The timing of illness can be related to the ability to cope.



Figure 5) Reality is made up of many components. Even if one aspect, for example physical illness or mental illness, is limiting, it is still possible to grow in other ways.

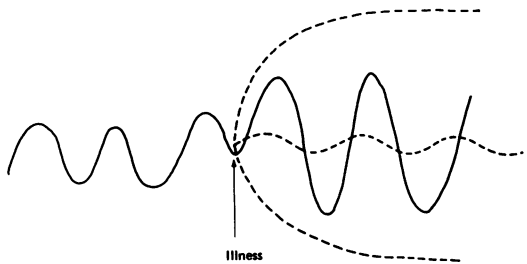


Figure 3) The impact of illness can have several effects on the quality of life, sometimes enhancing, sometimes diminishing.

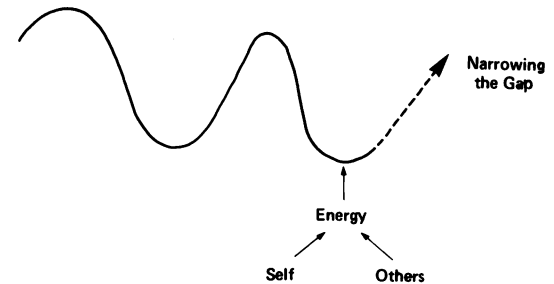


Figure 6) To grow requires energy, from the individual and/or others.

7) To increase the quality of life requires energy to change the height of the wave. This can either be self-generated or come from outside, from others. A variety of methods may be employed (Figure 6).

8) What about the 'man who has everything' yet is unhappy? Two explanations are possible. First, he may still not have what he really wants and still be searching. Secondly, overshooting the hopes may also lead to tension and stress. Over-promotion for example, or in patients an unexpected recovery, may be stressful to all concerned.

9) Could this concept of quality of life be of value to the caring team who may have to make decisions about initiating, or not initiating, treatment? The hypothesis

emphasises the fact that discussion with the patient is the only way to assess patient needs. Secondly, it may help in communicating with the patient when treatments have to be used which may have short-term side-effects but long-term benefits. Thirdly, it allows identification of future events which may be of special significance to the patient (anniversaries, births, weddings etc) when it may be acceptable to induce some side-effects, if short-term survival for a particular purpose is the objective.

In more general terms, could this hypothesis be of value in assisting in other treatment decisions, such as when to resuscitate a patient, or to switch off life-support systems, when the concept of subsequent 'quality of life' may be being considered? Under these

circumstances the use of the diagrams may be of value when discussing this with the caring team, and with the relatives. Because the reality may be seen to be very low, and the subsequent expectations also low it may assist in decision-making in specific circumstances. It may allow an assessment of the size of the gap between the present and future recovery.

### Evaluation

The hypothesis as described is essentially a problem-orientated or task-orientated approach to quality of life. As such it is similar to that developed in the *Nursing Process* (10) and in problem-orientated medical records (11). It is suggested that it is a pragmatic approach to the definition of quality of life, its assessment, modification and evaluation. It can be developed in these four stages.

- (i) Assessment. The patient's own list of problems and priorities, the estimation of the 'gap'.
- (ii) Development of a plan for modification of quality of life, with full involvement of the patient.
- (iii) Implementation of the actions identified to meet the specific needs.
- (iv) Evaluation of the outcome of the intervention and a review of the goals set.

Seen in this light it is hoped this concept of quality of life will stimulate further research into this difficult area.

### Conclusions

An hypothesis concerning the nature of the quality of life has been proposed and some of its implications developed in a diagrammatic way. It is concluded:

- (i) The instruments developed to measure quality of life must take into account many aspects of life and life-style.
- (ii) The problems and priorities which are important are those of the individual and not of the observer.
- (iii) Measurement of quality of life is not sufficient in itself. Action should be taken to improve quality of life

(to narrow the gap) either by making expectations more realistic or by encouraging the individual to develop and grow in other ways.

- (iv) The emphasis should be on the positive aspects of narrowing this gap and improving quality of life.
- (v) Evaluation of any intervention to modify quality of life is essential.

It is useful perhaps to remember the words of Dr Samuel Johnson: 'I know not anything more pleasant, or more instructive than to compare experience with expectation or to register from time to time the difference between idea and reality'.

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